



Judgment Day

On October 28, I walked down to neonatal after I gulped down my breakfast. I headed over to see Ryken and asked the nurse how the past few hours had been for him. Ryken was doing about the same, and no concerns were noted. Brett showed up after I pumped, and we spent time with Ryken at his bedside.

Ryken had been given twenty milliliters of my breast milk through a gavage tube. I was hopeful that the nutrition would make him stronger. I told myself we were on the mend—and that it was a good sign. He could grow with the nutrition he was getting because he was ten days old today.

We were notified that the head of neurology for pediatrics had come in from another city to assess Ryken and look over his case. There was a meeting set up for us with Dr. Dowry at one o'clock.

We went about our morning routine taking care of Ryken with the nurse, and kept a bedside vigil with him. I did my pumping and praying. Brett and I went to the cafeteria for an early lunch since we did not want to be late for our appointment. I was looking forward to the meeting with the doctors.

Ryken was doing so much better. I wondered what they would tell us about the brain swelling. Ryken's brain should have been completely normal by then, especially with how

well he was doing. There should be no more swelling of his brain was my thought. I had butterflies in my tummy as I ate. I was so excited to finally hear some good news.

We headed back up to the second floor in the elevator. We walked down the hall to the offices just outside of neonatal. I took a breath and knocked. The door opened, and we were invited in. As we stepped into the doctor's office, the introductions were made. Brett and I sat together on the loveseat.

Both doctors were behind the desk. They took turns speaking to us. "We have a diagnosis. The baby's glycine levels were elevated. Dr. Dowry, the pediatric neurologist, monitored him last night. He observed that the baby's arms were jerking, his tongue was moving, and his knees were drawn up."

This is nothing new except they possibly know what is wrong. I made myself focus on their faces.

"An EEG was repeated to assess the burst-suppression pattern in Ryken's brain since birth. The EEG was worsening, so the outcome is the probability of more severe seizures. The diagnosis we have is called nonketotic hyperglycinemia."

I was listening intently. I had no idea what Brett was thinking. My gaze was fixated on the doctors. As I listened, coldness gripped my body, and I shivered even though the temperature in the room was the same.

"There is no treatment for this condition. Ryken's convulsions will continue. This is part of the condition. There is a chance of this condition reoccurring in a subsequent pregnancy. The statistics are one out of four pregnancies, which means there is a 25 percent chance in each pregnancy that the baby will have this condition."

I was shaking inside, trembling from the truth that resonated in each syllable that was uttered to me. In every word that was relayed to us, my body was fighting against a frost that I could not escape. The cold was trying to settle in my heart. I would not allow it in.

“Each of you are a carrier of this condition in order for the baby to have it.”

This makes no sense to me. Brett and I are carriers of this condition? We did this to Ryken? How could this have happened?

Thankfully, my body provided a blanket of shock so I could cover up with it and keep my heart warm. I continued to listen.

The room began to feel hot and spacey. Reality settled in, but it was intermingled with numbness, disbelief, and a searing pain inside my heart. It was unbearable. I thanked God for these emotions because they allowed my brain to find the words to form a sentence.

I looked the doctors in the eye and said, “Are you telling me that my baby is going to die?”

I heard the answer to the question that I dared to ask. I so desperately needed an answer to the question, but I did not want to hear it.

The doctors look at me. The specialist said, “Yes.”

My brain was on overload. My world started to spin and became very small.

That is not the word I expected. That is not the word I wanted to hear.

I asked, “How long will he live?” I did not recognize my own voice. I was on autopilot. I was a zombie held captive within my own body. The magnitude of the truth that has just been spoken was too much for me to internalize. The truth was too difficult to comprehend.

Dr. Dowry said, “I have only worked with one other case of a baby who had NKH, and that baby lived for six months. That baby was given sodium benzoate. It is a medicine that helps to bring the glycine levels down in the body.”

What is glycine—and NKH and will sodium benzoate help Ryken?

It would not allow him to live forever. I heard the words “six months” again.

I felt as if we were trapped in the dark. The darkness that had fallen on our lives left no shadow or way to find the light. The light was no longer ours.

Brett and I listened in painful silence. We only had six months left with Ryken. That was a guess if compared to another baby who had the same condition. *This NKH, non-ketotic hyperglycinemia condition that my beautiful baby has just been diagnosed with.* If Ryken was barely two weeks old, we only had five and a half months left with him.

The walls were closing in around me, and I felt myself shutting down. The words I had heard left me immobilized. It was hard to breathe. I tried to maintain my focus. I felt like passing out, but I knew that I couldn't. I wanted to scream, but my voice didn't work. I wanted to shout out to them that they were wrong, but I didn't. My vocal cords had been tied in knots. The only thing they were capable of right then was stillness. I tried to focus on my breathing.

I wanted to hit something, but I kept my hands folded neatly in my lap. I wanted to ask God what we ever did to deserve this. I held my tongue. I remained silent.

I wanted to scream at the doctors to fix it. Instead, I looked at them quietly. I didn't like them even though they hadn't done anything. That was not true. I didn't even know them. I had nothing against them except that I didn't like the news they had given me. Would the truth set us free?

In our case, the truth left me shackled to a condition called nonketotic hyperglycinemia. We would never be free again. I couldn't even pronounce or spell the truth. This truth was written in our DNA, and now it was written in Ryken's.

The truth was Ryken's death sentence. Our genes collided because of our desire for another child. *We did this to Ryken.*

As the seconds slowly crept by, I heard the clock on the wall ticking. With each passing moment, my heart broke into tiny, shattered pieces. I was unable to keep the frost at bay as it engulfed my heart.

Words are powerful. They can be powerful enough to instill a ray of hope inside you or move mountains. They can be powerful enough to break your heart or shatter your dreams. The words we heard did the latter. I was expecting to jump on the ray of hope and ride it into the sunset when I left this room after our meeting.

Instead, the words left me breathless. I was unable to take a deep breath or speak. By breathing, you are living. I was breathing, which meant I was living. I was living, which meant I had to face reality. I had to face the truth.

The reality that they had bestowed upon us was that they had no lifesaving device for Ryken. They were going to stand on the shore and watch Ryken slowly drown. Before the meeting, Brett and I were hopeful that the two doctors would help us, and save our baby. We thought they would provide us with the best lifesaving device we could imagine. The reality—the truth—was that they wouldn't. Not because they didn't want to. The reality—the truth—was because they couldn't. I would despise having to tell parents that their babies are going to die.

I didn't care about them though. I was seething. The words that moved and swayed in my head were not kind. They were just there and they were not directed at anyone in particular. The feelings that moved through my body were not nice: rage, anguish, sadness, betrayal, hurt, pain, dread, shock, and denial. The smorgasbord of feelings was like nothing I had ever felt before. An indescribable helplessness was born from the truth. That was my new reality.

I was falling into a black pit of despair, and no one would reach out a hand to catch me and stop the fall. They just stared at me and watched as I fell deeper into the pit of unending pain and heartache.

With no words left to say, we left the doctor's office. Our first thought was Ryken, and we walked the fifty steps to see our baby.

With the news about his condition on my mind, I peered down at this treasure in front of me. Ryken looked like an angel as he slept. Soon he would become an angel.

His nurse asked us if we wanted to hold Ryken. I could see in her eyes that she knew our new reality. The nurse allowed us to hold him in the rocking chair beside his bassinet. Brett and I took turns holding our beautiful baby boy. We were very careful with all the cords and tubing attached to him. The machines were helping Ryken breathe and stay alive.

The air was thick with raw emotion, and there were no words that would make it evaporate. The rays of hope that had once danced playfully around Ryken's bassinet had stepped back to allow the impending rays of death to step forward and claim that space. Hope vanished, and doom had taken its place.

Brett gently passed Ryken over for my turn with him. I settled in the rocker and looked down at Ryken. He was sleeping peacefully. Tears streamed down my face, but I did not care. I snuggled him as gently as I could—even though I wanted to hug him tightly to my broken heart. I never wanted to let him go. I never wanted to face the words I had just heard.

I wanted to wake up from that nightmare and pretend it was only a dream—a crazy dream that we could laugh at. I could take comfort from our family and friends as they reassured me that babies don't die in real life. In real life, my baby did not have any kind of condition. In real life, my baby was healthy and thriving. I would watch him grow up with Kaden. I would see him play hockey and fight with his big brother.

I looked into Ryken's face. My little "Champion" was so precious and special. I rocked him and wept. I wept about the news that I only had five and a half months left with him. I wept with the reality that maybe I did not even have that long. I wept with the pain of a mother who could not do anything to help her child. Praying had done nothing. God

had ignored me. I felt the anger rising within me. I was so sad that the anger would not win right then. Despair was the winning emotion that claimed the space in my mind and body.

After a few moments, I passed Ryken over to Brett. I was trying to be mindful to share him. I saw the pain in Brett's eyes. I was overcome with the awful, cruel news. *What about all my prayers to God when I pumped and prayed? I asked God for a miracle? This is not a miracle. This is a cruel twist of fate. I can't believe this is happening to us.*

The social worker came over to talk to us. In a way, it was nice to see a familiar face. However, I did not want to see anyone I knew: acquaintance, family member, or friend. For a moment, I wondered if it was more difficult for her since she knew me.

She told us she was sorry to hear our news. Her advice was to keep a journal and write everything down in it. She would be there to help us, and she left her card if we needed to contact her for anything. We thanked her, and she left.

When will I have time write in a journal? How am I supposed to do that? All I wanted to do was hold Ryken before he died. I cried again silently.

My mind moved forward to the next thought. I was thankful that Kaden was on his way to the hospital. I wanted a family picture. I needed a family picture before it was too late—before Ryken was gone.